

VII. NFCSP SERVICE COMPONENTS

The National Family Caregiver Support Program (NFCSP) calls for the aging network to develop and coordinate a range of high-quality caregiver services linked through a system to enable caregivers easy access to the right service at the appropriate time. Building a strong system infrastructure, as described in *Chapter IV*, is the foundation to implementing services that are truly integrated, flexible, responsive to caregivers' needs, and sustainable. Though many programs and services provided in home- and community-based settings benefit caregivers, many of the benefits are incidental to services received by the older or disabled adult. The NFCSP provides the network with an opportunity to consider caregivers' unique values and needs and to create a service system that better meets the family's needs and preferences.

This chapter addresses the major service components of the NFCSP:

- **Information** for caregivers about available services;
- **Assistance** for caregivers in gaining access to these services;
- **Individual counseling, support groups, and training** to help caregivers make decisions and solve problems relating to their caregiving roles;
- **Respite care** to temporarily relieve caregivers from their caregiving responsibilities; and
- **Supplemental services**, on a limited basis, to complement care provided by caregivers.

Within this chapter are service descriptions and program examples of these five components, and a discussion of implementation issues. Based on current service activities that network agencies are pursuing as well as the interim guidelines that the Administration on Aging (AoA) issued on October 31, 2001 (see *Appendix A*), the service descriptions reflect a broad range of options for the network. The service definitions for Title III-E are expected to evolve over the next year as part of the Title III information system refinement process, spearheaded by AoA with the assistance of aging network representatives.

Program examples are provided to illustrate a range of strategies for designing and implementing caregiver services. Some of the program examples represent multi-component approaches that might reside in more than a single service category. Such approaches manifest the flexibility the NFCSP affords. Just as the needs, experiences, and preferences of caregivers vary, caregiver support interventions differ and must be designed to account for the heterogeneity of both caregivers and localities.

Under the NFCSP, the care recipient must have two or more activities of daily living (ADL) limitations or a cognitive impairment for the caregiver to be eligible for respite or supplemental services. (See Section 373(c)(1)(B) and its footnote to the "Frail Elderly" Section 102(26)(A)(i) or (B) of the NFCSP Act in *Appendix A*.) Some of the respite care

and supplemental service examples described later in this chapter have been supported by state or other non-Title III-E sources and therefore are not bound by this eligibility restriction.

The chapter emphasizes several overarching principles for designing and implementing caregiver support services:

- Seek flexible approaches to service design and delivery to meet caregivers' diverse needs and preferences.
- Monitor, evaluate, and modify services on an ongoing basis.
- Leverage resources through service integration and the use of partners and volunteers.
- Invest in personnel skills and training to reach caregivers at the “servable moment.”
- Coordinate services so program delineation is invisible to the caregiver and so the services enhance, not duplicate, the caregiver program.

INFORMATION

Service Description

Information refers to individual and group services, including public education, provision of information at health fairs and other similar designations as determined by the state, that inform caregivers of available services. Information is inclusive of outreach activities—interventions initiated by an agency or organization for the purpose of identifying potential clients and encouraging their use of existing services and benefits. Information can include both group and individual contacts but, for reporting purposes, service units for information signify individual, one-on-one contacts between an information provider and a caregiver.

The aging network can pursue a broad range of activities in local communities to reach individuals of diverse caregiver populations. *Exhibit VII.1* presents a spectrum of information activities for caregivers planned by the aging network or under way.

Exhibit VII.1 Strategies to Provide Information to Caregivers

<ul style="list-style-type: none"> ▪ Conduct outreach through caregiver fairs. ▪ Target working caregivers through employee assistance programs (EAP) and Human Resources departments. ▪ Contract with the publisher of a local senior newspaper to include “Caregiver Corner” columns. ▪ Purchase computers with large-screen monitors to place in senior centers for caregiver access to the Internet. ▪ Enhance Web sites with links to caregiver information. ▪ Develop “caregiver survivor kits”. ▪ Develop resource guides for caregivers. 	<ul style="list-style-type: none"> ▪ Provide a caregiver information bookmobile or resources-mobile. ▪ Subcontract with an ethnic community organization for outreach. ▪ Provide one-on-one contact and counseling to targeted caregiver populations. ▪ Develop a media campaign and community outreach effort in collaboration with providers, such as congregate meal sites, legal aid or insurance counselors, and senior centers. ▪ Create an interactive Web page: <i>Caregiver Journal Exchange</i>. ▪ Hire caregiver resource specialists. ▪ Make caregiver resources available on video.
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Strategies and Program Examples

Align Information Activities with Caregiver Program and System Development Goals to Facilitate Desired Outcomes. Strategies to provide caregivers with information about available resources should reflect programmatic goals in terms of the type of information needed, target audience, methods to circulate information, and desired message. In conceiving information strategies, the network should process the knowledge gained from needs assessment, focus group, advisory council, and other activities. ***Exhibit VII.2*** presents the Minnesota Board on Aging’s (SUA) approach to reach caregivers with service information as it relates to the goals of the wider system change activities taking place in the state.

Exhibit VII.2

Communication for Caregiving in Minnesota

Overall Goals of the Project	Goals of Caregiving Communications	Potential Audiences
<ul style="list-style-type: none"> ▪ Improvement in quality and duration of care provided by informal caregivers ▪ Reduction of long-term care expenditures ▪ Strengthening of the caregiving network in Minnesota, both formal and informal 	<ul style="list-style-type: none"> ▪ Raising of public awareness of caregiving ▪ Education of caregivers about services that could assist them as a caregiver, with special targets. ▪ Education of businesses about the impact of caregiving on workers and enlistment of their support in educating employees about caregiving resources in their communities ▪ Raising of public awareness of individual responsibility for long-term care planning and preparedness. 	<ul style="list-style-type: none"> ▪ Spouses who provide care ▪ Adult children who provide care ▪ African American and Hispanic women, Hmong caregivers ▪ Businesses and other employers ▪ General public

Explore Traditional Settings, as well as New Locales, Through Which the Aging Network Can Distribute Information to Caregivers. The aging network will want to reach caregivers at health fairs, senior centers, and other traditional venues. The NFCSP encourages agencies to expand their efforts to other locales exhibiting potential to tap into the caregiver market (e.g., businesses, schools, community clinics, churches, and hospice organizations). ***Exhibit VII.3*** details examples of network strategies to reach caregivers through the military, medical, and faith communities.

Exhibit VII.3

Expanding Outreach to Caregivers

<p>Title: Information and Outreach with the Military</p> <p>Affiliation: Mid-Carolina AAA in Fayetteville, NC</p> <p>Status: Operational</p> <p>Target Population: Individuals in the military, veterans, and their families</p> <p>Approach: The caregiver specialist at the AAA contacted the Veteran's Administration (VA), the VA nursing home, Family Services (social workers for the military), the Family Readiness Programs, and insurance carriers to discuss caregiver support and open channels to reach these individuals. This process involves a coordinated effort between the military and civilian communities to provide information, education, and services available to all military affiliated caregivers at the community level. Outreach information is provided through many venues such as newsletters; the Moral, Welfare and Recreation (MWR) division; hospitals; and grocery stores.</p> <p>Contact Information: Kristina Dice, Family Caregiver Resource Specialist, Region M, Mid Carolina AAA, at kdice@fayetteville.net or (910) 323-4191 ext. 28.</p>

Exhibit VII.3 Expanding Outreach to Caregivers, continued

Title: Information and Outreach through Physician Offices

Affiliation: New Mexico State Agency on Aging

Status: Developmental (Suggestion for outreach under the NFCSP being considered)

Target Population: Office nurses that provide information to caregivers

Approach: The SUA is considering options for outreach to caregivers under the NFCSP including an adaptation of a successful program used elsewhere with Pediatric nurses. In the model program, flyers were sent to physicians' offices to offer education for office nurses on what is available for caregivers. The training explained how to access services so nurses can provide caregivers with necessary information and connect them to services. The training was held once a month during lunch or on a day that the clinic closed early.

Contact Information: Barbara Owens, Program Manager, New Mexico State Agency on Aging, at Barbara.Price-Owens@state.nm.us or (505) 255-0971 ext. 104.

Title: Outreach through Collaboration with the Faith Community

Affiliation: Northwest Regional Council, AAA (Washington) and Community of Faith Outreach

Status: Operational

Target Population: Caregivers known to faith communities

Approach: Northwest Regional Council, AAA contracted with an individual to liaison with the Community of Faith Outreach program to reach "hidden" caregivers in faith communities. The program raises awareness of caregivers' issues and provides recommendations on how to support caregivers and refer individuals to resource specialists. Through this collaboration, over 100 faith communities have been contacted and more than 50 presentations conducted.

Contact Information: Kim Boone, Northwest Regional Council, AAA at boonkb@dshs.wa.gov or (360) 676-6749.

Provide Information about Available Resources in a Targeted and Timely Fashion.

Non-specialized and limited availability of information might contribute to a lack of awareness of existing services and, even when caregivers are aware of resources, an inability to apply them to their own needs.¹ Information about services must be tailored to different caregiver needs in terms of the type of information (e.g., disease related) and the strategy employed. **Exhibit VII.4** lists effective outreach strategies to different ethnic populations, emerging from the seven-year Alzheimer's Demonstration program that ran in Washington State from 1993–2000. The outreach materials and strategies developed for Chinese, Korean, Hispanic, and Native American communities under the demonstration might be a helpful resource for the aging network in enhancing outreach methods and targeting previously underserved populations. (See <http://www.aoa.gov/alz> for more information.)

¹ Coyne, A. (1991). Information and Referral Service Usage Among Caregivers for Dementia Patients. *The Gerontologist*. 31(3): 384–388.

Exhibit VII.4

Effective Outreach Strategies to Ethnic Communities

- Use face-to-face contact and an informal one-on-one approach that is slow paced, allowing time to build trust.
- Partner with existing community organizations such as family associations, women's groups, and professional associations to spread the word. Request that your program be part of their meeting agendas.
- Make your services visible in the targeted community through local businesses, local media, and community events. Ask ethnic-based business owners to distribute brochures.
- Ask organizations to let you host a "resource table" at a community event.
- Cast a broad net and consider making presentations focusing on broad issues of aging, caregiving, and long-term care.
- Form collaborations with community health providers to bring referrals to the program.
- Help an individual or family with an immediate need rather than expect them to discuss sensitive issues surrounding dementia or other long-term services.

Source: AASA, 2000. Pamphlet, Description of Effective Washington State Alzheimer's Disease Demonstration strategies.

Marketing to caregivers requires new strategies, materials, and techniques. In providing information about services, the network must use language that seems responsive to caregivers. The term "caregiver" is unfamiliar to many people—caregivers identify themselves as wife, husband, daughter, son, partner, or friend. Similarly, "respite care" and "support group" might fail to resonate with caregivers who desire "a break" and "peers to talk to." The National Family Caregivers Association (NFCA) and the National Alliance for Caregiving (NAC) have joined together to conduct the first phase of a two-phase intervention, The Family Caregiver Self-Awareness Project. The goal is to produce a comprehensive communication campaign aimed at family caregivers that incorporates specific tested messages and recommended interventions to change how family caregivers perceive themselves and behave in their role. The project team will apply social marketing principles, focusing on the perceptions and needs of family caregivers. In addition to developing effective messages for caregivers, the team will explore a range of message delivery options based on research. Further information about this project can be obtained through NFCA's Web site at <http://www.ncfacades.org/>.

In addition to receiving information intended for them, caregivers need timely information. When information is not received in a timely manner and when questions or concerns go unanswered, caregivers tend to give up and make the best of their situation. This circumstance leads caregivers to access the system at points of crisis. Likewise, outreach efforts must accommodate differences in caregivers' receptivity (using Montgomery's "marker framework") and be tailored to caregivers' specific needs. Some examples of planning and service activities to aim caregiver outreach at different career markers include:

- Sponsoring an annual “Rake the Town” community event to help identify caregivers. (contact: Linda Giersdorf, Director, Region Nine AAA in Mankato, Minnesota, at lindag@rndc.mankato.mn.us)
- Conducting outreach to caregiver support group attendees to inform caregivers about additional services as well as learn from them ways to connect with caregivers who might fail to identify with that role. (contact: David Hanson, Program Specialist, Pierce County Aging and Long Term Care, AAA in Lakewood, Washington, at dhanson@co.pierce.wa.us)
- Establishing an advisory council of caregivers and interested professionals to offer advice about reaching individuals who care for others but might fail to identify as caregivers. (contact: David Hanson, information same as above)
- Targeting family caregivers of older persons who have been placed in or are transitioning back to the community after receiving care in skilled nursing facilities and offering them assistance, support, education, and empowerment. (contact: Robert Sessler, Director, Contra Costa County Aging and Adult Services Bureau in Martinez, California, at [925] 313-1605)

Disseminate Information in Various Formats Responsive to Different Caregivers’ Preferences. Findings from the 1998 NAC survey and other empirical evidence suggest that more caregivers would like to receive information about caregiving in written form than another information channel.² Agencies might want to develop resource guides for caregivers in partnership with other entities (e.g., the local Alzheimer’s Association chapter). The guides could then be distributed to other community entities such as social service agencies, major employers, hospitals, and home health agencies.

Still, caregivers desire information through a variety of channels, which the aging network should consider in meeting their diverse needs. ***Exhibit VII.5*** showcases two individual face-to-face outreach strategies. A segment of the caregiver population is growing accustomed to seeking information via the Internet. Supporting caregivers’ information needs might involve, for example, producing materials that list Web resources for caregivers or developing or enhancing agency Web sites that contain specific information for caregivers, including hypertext links when appropriate. Sites could offer caregiver calendar events, access to one-on-one dialogue, and other means of information dissemination. To gain a better sense of the utility and response to the site, agencies can track hits (i.e., visits to the Web site). Also, because caregivers often seek information through the medical community, the aging network should consider bridging with local medical Web sites (e.g., community hospital, home health care, hospice, disease associations, outpatient clinics, nursing facilities, academic medical centers/Institutes on Aging). Regardless of its design and features, a Web site is only as good as its information. Therefore, a critical, albeit time-consuming, activity, content should be maintained on a regular basis. For further information about Internet applications for caregivers and the aging network, see ***Chapter IX***.

² National Alliance for Caregiving. (September, 1988). *The Caregiving Boom: Baby Boomer Women Giving Care*. Prepared by the National Alliance for Caregiving, Bethesda, MD.

Exhibit VII.5

Individual Face-to-Face Outreach Examples

Title: Mobile to Immobile Caregiver Outreach Program

Affiliation: Southwest Missouri Office on Aging (AAA)

Status: Operational

Target Population: Geographically -isolated caregivers

Approach: The AAA launched a two-year outreach program in June 2001 in which a staff member and a specially equipped van with caregiver information are assigned to an isolated geographic area. The program targets older individuals in the especially rural areas of Oregon and Shannon counties. The program has been successful largely because the mobile outreach coordinator has been an employee of the AAA for 20 years and has the trust of the communities' residents. Since the program's start, 68 caregivers have been assisted with accessing benefits and service coordination. Referrals generate from other AAA-sponsored activities in the communities.

Cost/Funding: The program is funded through a grant. Expenses include a fulltime employee's salary and fringe benefits, a used van, and van supplies (i.e., fax, cell phone, and laptop).

Contact Information: Dana Cain, Project Coordinator for Technology Education and Assistance for Missouri Seniors (T.E.A.M.S.) Project, Southwest Missouri Office on Aging, at dana@swmoa.com or (417) 862-0762 or (800) 497-0822.

Title: Caregiver Resources and Book Mobile Program

Affiliation: Piedmont Triad Council of Governments Area Agency on Aging, North Carolina

Status: Developmental

Target Population: Caregivers of elders known to the service system, grandparents raising grandchildren, caregivers of adult children with MR/DD, and caregivers who have not self-identified as such

Approach: The AAA is pursuing a regional library initiative to collaborate with public libraries in providing caregiver resources in their seven-county service area. The majority of counties in the region have a book mobile that extends to seniors' homes, senior centers, and nursing homes. Using the reputation of a library, the program seeks to reach an otherwise isolated population through a non-threatening and credible institution. The AAA is building on this effort to ensure that caregiver literature is available with the book mobile program. Each county's planning committee, comprising service providers, community members, and county commissioners, developed partnerships with the local public library by sharing caregiver resources with the library administrators during committee meetings. The book mobile drivers will now serve as a distribution source and depository of caregiving information (i.e., video or audio materials, books, information on seminars and community events). Plans include educating the drivers to identify caregivers and helpful resources.

Cost/Funding: Because it has built an existing infrastructure, the program has minimal costs beyond developing marketing materials for the caregiver program. Service providers supply service information materials for distribution. NFCSP dollars might be used in the future to fund the driver education piece.

Contact Information: Blair Barton-Percival, Aging Program Specialist, Piedmont Triad Council of Governments, at bbpercival@ptcog.org or (336) 294-4950.

ASSISTANCE

Service Description

Assistance refers to a service that assists caregivers in obtaining access to the services and resources available within their community. The major form of assistance this chapter discusses is information and assistance (I&A).³ I&A is a service that provides current information on available opportunities and services; assesses the problems and capacities of the individuals; links the individuals to the opportunities and services; and ensures, to the maximum extent practicable and by establishing follow-up procedures, that the individuals are aware of the opportunities and receive the services needed. I&A represents a key component of a multifaceted system that supports caregivers. The NFCSP gives the network an opportunity to review their existing I&A system to evaluate how it can better serve caregivers and minimize the confusion and frustration of families seeking information, services, or both.

Care management (support coordination) is another method of assistance, either in the form of access or care coordination, in circumstances where the older person or his or her caregivers are experiencing diminished functioning capacities, personal conditions, or other characteristics which require the provision of services from formal service providers. Activities of care management include assessing needs, developing care plans, authorizing and arranging services, coordinating the provision of services among providers, and conducting follow-up and reassessment, as required. The network varies in how it organizes care management. Some agencies tie it closely to I&A functions, while others operate relatively freestanding care management systems. State Units on Aging (SUAs) and Area Agencies on Aging (AAAs) can pay for care management out of Title III funds. *Chapter VI* gives a full description of care management for caregivers and the related activities of assessment and care planning.

Strategies and Program Examples

Adjust I&A Systems to Respond to Caregivers' Needs. Any I&A system should recognize that caregivers are customers in their own right. They have needs related to the care recipient's needs, and they have needs distinct from the care recipient. If caregivers' needs are met at the right time, they more likely will seek assistance again. Also, because people can use only the information they are prepared to grasp, I&A systems function more effectively when they avoid overloading caregivers with materials. In recognizing caregiver diversity, I&A systems should be equipped to address the needs of different types of caregivers and account for caregiver career variation and other unique circumstances. For example, some of the caregivers in contact with an I&A system are

³ The term information and assistance (I&A) used in this Resource Guide refers to what some call Information and Referral (I&R) or (I&R/A).

“information seekers” and some are “service seekers,” requiring staff to detect the difference and assist appropriately.⁴

Although many caregivers will continue to use the telephone to connect with the system, a segment of the population will take advantage of the Internet as their first resource. Agencies will want to consider designing online I&A databases that allow caregivers to “self serve,” a particularly convenient format for workforce participants and long-distance caregivers. When designing an online resource, then, agencies must ensure that information available via the Internet is compatible with the information dispensed to caregivers by telephone. **Exhibit VII.6** offers a snapshot of Eldercare Solutions, an I&A-based resource referral product for working caregivers.

Exhibit VII.6 **Self-Serve I&A for Working Caregivers**

Title: Elder Solutions

Affiliation: CICOA the Access Network (Indiana AAA)

Status: Operational

Target Population: Working caregivers

Approach: CICOA developed Elder Solutions, an I&A-based resource referral product for working caregivers, on the premise that with easy access to information and services, the loss of work time will decrease while company productivity and, consequently, revenue will increase. In addition to I&A, Elder Solutions distributes a quarterly newsletter; maintains a dedicated phone line and an email address for a broad array of questions; and conducts onsite events, including staff training, employee consultation, resource kiosks, and seminars on specific caregiving topics. The AAA targets companies with 100 to 500 employees. Companies’ receptivity to this product has led Elder Solutions to now include an assessment for the caregiver and care recipient. CICOA marketed Elder Solutions through the use of paid advertisements, articles, brochures, and results from an Eldercare survey completed by employees of five companies. The results of this survey, which clearly show the need for employer support, have proven the most effective marketing tool because they negate employer beliefs that caregiver issues represent no problem. The AAA has found that employers respond more positively when they are experiencing their own eldercare issues.

Cost/Funding: Pricing for Elder Solutions is based on the number of employees. CICOA used philanthropic funds to develop and market the service.

Contact Information: Thomas Otto, Executive Vice President and COO, CICOA, the Access Network, at totto@cicoa.org.

⁴ Montgomery, R.J.V. Presentation at the AoA Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

Build I&A Capacity to Achieve Overall Systems Development Goals. Personnel, training, standards, requirements, information technology, protocols, and linkages must be addressed to ensure that systems are flexible to meet the I&A needs of caregivers. Agencies will want to consider several options, such as extending hours of I&A telephone staff, purchasing computers and database software, exploring opportunities to coordinate with other I&A providers, and creating positions to provide assistance specifically for caregivers. As ***Exhibit VII.7*** shows, several movements at the national level are helping shape systems across the country, offering guidance to the network in building capacity.

Exhibit VII.7 National Information and Assistance Movements

The **Alliance for Information and Referral Systems (AIRS)** has developed a set of standards for effective I&R and a classification of I&R terminology. AIRS also offers an accreditation program as well as a certification program for I&R providers. See <http://www.airs.org/>.

Eldercare Locator and the **National Aging I&R Support Center** were introduced in 1991. Beginning as a telephone line (1 [800] 677-1116), Eldercare Locator connects elders and their caregivers with information providers nationwide. It is administered by the National Association of Area Agencies on Aging (N4A) in cooperation with the National Association of State Units on Aging (NASUA). Now Eldercare Locator is available online, as well, allowing caregivers 24-hour access. The Support Center has assisted many SUAs and AAAs with I&A system redesign, developed and operationalized standards, conducted training and certification, and tracked emerging technologies. The Support Center has been working with AIRS to develop an aging I&R specialist certification and examination, expecting to launch in spring 2002. See <http://www.eldercare.gov/> and <http://aoa.gov/naic/>.

Aging Connection Plus was created by the Atlanta Regional Commission, stemming from the commission's development of the CONNECT database—the foundation of Georgia's entire aging and long-term care information system. The software (developed by CyberPath, Inc.) used for this system, Elderly Services Program (ESP), includes categories and services for traditional and nontraditional services. Businesses and community organizations can subscribe to the fully automated, comprehensive, and maintained Aging Connection Plus database of more than 4,000 providers and 8,000 services for an annual fee of \$5,000 to \$10,000. CyberPath now makes the software database packages available for AAAs outside the state of Georgia. See <http://www.agingatlanta.com/agingconnectionplusindex.html>

The **211 Movement** first started in Atlanta, Georgia, and now more than 15 states have adopted it. The movement refers to the designation of 2-1-1 by the Federal Communications Commission as the abbreviated dialing code for human services information. See <http://www.211.org/>.

NASUA Vision 2010: Toward a Comprehensive Information Resource System for the Next Century is a framework established to guide I&A systems in coordination, comprehensiveness, technology, personnel, marketing and outreach, responsiveness, knowledge building, and leadership. As it relates to caregivers, Vision 2010 aims to develop a caregiver information and assistance system that is broad based, empowers caregivers, supports caregiver choice, uses appropriate technology to provide timely assistance, and includes evaluative and caregiver satisfaction components for setting direction and assessing value. See <http://www.nasua.org/>.

In building capacity, the need for information and assistance is great for people who fail to qualify for public assistance. The aging network will have to consider provisions to treat I&A as a distinct service and method of reaching the general public and not just for individuals seeking publicly funded services. In Wisconsin, for example, counties operate Aging and Disability Resource Centers offering information and assistance to older adults and their families of all ages and incomes. It has been argued that by receiving help with making effective long-term care choices, middle- and upper-income older adults and their families will use their private resources more efficiently, thereby reducing the chances of exhausting all their resources and relying on more costly publicly-funded services.⁵

Develop Strong Leadership at the State and Local Levels. Theresa Lambert of NASUA suggests that the network provide leadership to address the I&A needs of caregivers through the following:⁶

- Creating the vision for I&A in the NFCSP;
- Establishing organizational structure and internal leadership to initiate and sustain caregiver focus (e.g., advisory committee, caregiver champion, caregiver advocacy);
- Promoting the strengths of the current I&A system, identifying its weaknesses, and developing plans to meet those challenges;
- Ensuring continuous quality assurance and improvement of I&A systems to adequately respond to caregivers while empowering caregivers to recognize their own role and needs;
- Developing new partnerships that increase coordination and decrease duplication;
- Securing additional resources as might be required to achieve the vision (agencies should investigate the extent to which the state is willing to supplement OAA funding for I&A); and
- Designing data collection systems that capture meaningful information and can inform the systems change process, service development, advocacy, etc.

Pursue Internal and External Coordination. Reinhard and Scala reported that more than 3,500 OAA-funded I&A programs exist across the country that greatly differ in their effectiveness in reaching older adults and families with I&A.⁷ In developing or enhancing I&A support for caregivers, states should review their current systems for possible ways

⁵ Reinhard, S.C. and Scala, M.A. (2001). *Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States*. Prepared for the Public Policy Institute, AARP.

⁶ Lambert, T.N. (2001). *Information and Assistance*. Comments on Cheryll Schramm's issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

⁷ Reinhard, S.C. and Scala, M.A. (2001). *Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States*. Prepared for the Public Policy Institute, AARP.

to streamline their efforts both internally and externally with other I&A providers. Cheryll Schramm suggests focusing on the following coordination activities:⁸

- **Internal.** An essential step of systems development is the coordination between the I&A service and other aging programs with an information and assistance component (i.e., Long Term Care Ombudsman, SHIP [Senior Health Insurance Information Program], APS, legal hotlines, pension counseling, and care management). Staff from other programs must be educated about the role and function of the I&A service under the NFCSP and be able to link caregivers to that service. For many states that have no statewide databases, the NFCSP presents an opportunity to evaluate the prospect of developing a centralized database and a classification of service terms.
- **External.** In building multifaceted systems of support, coordination with external statewide and regional I&A providers—both nonprofit and for-profit—must occur. The NFCSP legislation calls for the aging network to address the needs of other caregiver populations (i.e., grandparents raising grandchildren and older persons caring for children with developmental disabilities), which requires coordination with external agencies that have their own I&A systems. Such coordination offers the network an opportunity to: 1) educate others about the aging I&A system and the NFCSP; 2) receive education and training surrounding grandparent issues, kincare, communicating with caregivers caring for individuals with development disabilities, etc.; and 3) develop integrated resource databases that are population-specific and can be tailored to individual user needs. In addition to coordination with disability, children, and youth I&A services, SUAs, AAAs, and ITOs should coordinate with 211 for human services information, whether pursuing formal integration or simply ensuring proper referral mechanisms.

Different strategies exist for building I&A systems that support caregivers. When considering a strategy, two primary concerns should be whether to combine aging and caregiver I&A or create a designated I&A system for caregivers and whether to develop a statewide system or a regional one. Further, agencies must ask themselves if the I&A will be in house and which staff will assume responsibility for assisting caregivers.

The AAA in Pierce County, Washington, for example, contracts with the city of Tacoma to deliver I&A. The AAA maintains an in-house team of five, with one position dedicated to the Family Caregiver Support Program (FCSP). They decided to structure the FCSP I&A in house to better connect caregivers to available resources. The AAA educated providers to refer caregivers to the in-house I&A number; if a caregiver calls the city of Tacoma I&A, automatically he or she is referred to the in-house system. The AAA is also considering the creation of a caregiver telephone hotline in collaboration with the crisis and information line and with the Tacoma YWCA. The hotline would enable caregivers who either have insufficient time to attend a support group or have no one else to help

⁸ Schramm, C. (2001). *Information and Assistance: Where We Are . . . Where We Can and Should Be*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

care for the care recipient to receive the support they need. Trained providers and volunteers would staff the hotline.

Exhibit VII.8 showcases an I&A approach at the local level in Ohio that involves coordination with Catholic Social Services and the Alzheimer’s Association.

Exhibit VII.8 Local Level I&A Coordination

Title: Caregiver Help Lines

Affiliation: Council on Aging of Southwestern Ohio (AAA in Cincinnati, Ohio), Alzheimer’s Association, and Catholic Social Services

Status: Developmental

Target Population: Caregivers of older adults with and without dementia

Approach: The AAA is arranging I&A lines specifically for caregivers. One help line operated by Catholic Social Services through its Caregiver Assistance Network uses trained current or former caregivers to provide counseling, information, and support over the telephone. The Caregiver Assistance Network also works with area community organizations and senior centers to reach caregivers. The other help line will be run through the local Alzheimer’s Association to provide similar support for caregivers of seniors with Alzheimer’s Disease or related dementia (ADRD). This design is based on its finding that caregivers of individuals with ADRD need professional education about disease process, suggestions about behavioral management, and specific safety issues. Typically, non-dementia caregivers need someone to talk with, and they respond well to empathic people who have “walked in their shoes.”

Cost/Funding: The program costs approximately \$160,000, and most funding comes from Title III-E funds. The funding supports: 1) the network of support groups linked to the information lines, including staff to train volunteer facilitators, advertising, and occasionally professional speakers; 2) staff and volunteers for the help lines; and 3) workshops for caregivers in the community sponsored by both agencies.

Contact Information: Gene McClory, Caregiver Assistance Network, Catholic Social Services, at (513) 241-7745; Clarissa Rentz, Alzheimer’s Association, at (513) 721-4284.

Establish Uniform and Consistent Messages for Single Point-of-Entry Systems, While Maintaining Local Flavor. A number of states (e.g., New Jersey, Indiana, Wisconsin, Minnesota, Georgia, Iowa, and New Mexico) are further developing their I&A service by pursuing single-point-of-entry systems. They are attempting to establish uniformity and consistency of information for consumers, while maintaining the individuality of the local organizations (particularly a strong county-based system which requires negotiation and adaptation).

Georgia’s Aging Connection I&A system and CONNECT database resulted from a long process that began at the local level before statewide expansion. In the development phase, the Atlanta Regional Commission chose to manage the system at the regional AAA for the 10-county area. The commission convened a steering committee to advise the development and formulate a vision and goal for the system. **Exhibit VII.9** describes this development process in further detail, while **Exhibit VII.10** describes New Jersey’s experience in pursuing comprehensive statewide I&A reform with the Easy Access, Single Entry (EASE) program.

Exhibit VII.9

Development of Aging Connection and CONNECT Database

Atlanta Regional Commission (AAA in Atlanta, Georgia)

- Maintained an inventory of internal resources—costs, available funding sources, potential funding sources, staffing requirements, adequacy of the agency structure for development.
- Continually analyzed the geographic area—how the health and human service infrastructure affects the implementation or expansion of I&A, political considerations, involvement of the business community, how special needs populations should be included, and how demographics influence development and expansion.
- Identified the potential users.
- Named the system and developed a tag line that will speak to the audience (caregivers).
- Decided what information to collect, the collection method, and the use of the data.
- Developed a follow-up system to measure client satisfaction.
- Developed a provider database along with a classification of aging and LTC services. (The Atlanta Regional Commission selected ESP software developed by CyberPath, Inc.)
- Developed Aging Connection Plus, a fully automated and comprehensive database of more than 4,000 providers and 8,000 services marketed to business and community organizations, with an annual subscription cost of \$5,000 to \$10,000.
- Purchased additional software that interfaces with the ESP software allowing a client screen that measures need through activities of daily living (ADLs) and instrumental activities of daily living (IADLs), care recipient assessment instrument and care plan linked to the provider database, and a brief caregiver assessment tool.
- Expanded the database for uniformity and accessibility throughout the state of Georgia.
- Integrated the database with other LTC programs to support the Medicaid Waiver programs, SHIP, the Corporate Eldercare program, and the Aging Information Network and the Senior Employment Referral program.
- Provided ongoing training and required AIRS certification of I&A specialists in Georgia. (The training involves the requirement to explore the unique needs of the caregiver in addition to the needs of the older adult.)
- Created a Web site, <http://www.agingatlanta.com/>, that links to the CONNECT database and allows users to search for information and services and correspond with staff via email.
- Developed an ongoing collaborative effort with community organizations to further enhance the I&A system (e.g., Greater Georgia Alzheimer's Association, Jewish Family and Career Services, and United Way 211).

Exhibit VII.10

Comprehensive Statewide I&A Reform in New Jersey

Title: NJ EASE (Easy Access, Single Entry)

Affiliation: New Jersey Division of Senior Affairs (SUA)

Status: Developmental

Target Population: Older adults and their caregivers

Approach: NJ EASE is a statewide initiative led by the New Jersey Department of Health and Senior Services in partnership with county governments and local agencies. A unit of the SUA works with each county on system design to provide core services (i.e., information and referral, assistance and outreach, screening, comprehensive assessment, care planning, and care management) through the use of standardized assessment instruments, service coordination protocols, care management standards, and staff training. In addition, the program established a single nationwide toll-free number for consumers to learn about and access services that address financial, medical, and social needs; created a uniform resource directory; and launched a public awareness campaign to encourage consumer use of NJ EASE services. The SUA allowed counties the flexibility to adapt the program to best meet their local needs. The I&A staff must attend a mandatory three-day training session (NASUA based), and care managers must attend a four-day training, with an optional seven-day advanced training. Current plans are to incorporate caregiver components into NJ EASE, including caregiver assessment tools, staff training about caregivers, caregiver service coordination policies and protocols, and a caregiver resource Web site.

Cost/Funding: The state of New Jersey, under the auspices of the governor's office, received a \$238,251 grant from the Robert Wood Johnson (RWJ) Foundation in December 1994. Together with \$400,592 in matching state monies, the grant supports NJ EASE planning. The state currently has a Title III-E National Innovation Grant from AoA to help develop the caregiver components of NJ EASE.

Contact Information: Barbara Fuller, Program Manager, New Jersey Division of Senior Affairs, at barbara.fuller@doh.state.nj.us or (609) 943-4060.

For further information about building a comprehensive I&A system, see Reinhard and Scala's 2001 manuscript for AARP.⁹ (See *Appendix B* for a self-assessment chart for states considering comprehensive statewide reform [adapted from the framework used in the AARP manuscript]).

Invest in Personnel Because They Are Vital to Effective I&A Service Delivery. The success of an I&A system relies on the staff's capacity to respond to an increasingly diverse caregiver and care recipient population—their ability to interpret, ask the right questions, make the proper referrals, and conduct adequate follow-up. I&A staff should be viewed as “knowledge brokers” skilled at analyzing, synthesizing, and creative

⁹ Reinhard, S.C. and Scala, M.A. (2001). *Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States*. Prepared for the Public Policy Institute, AARP.

problem-solving.¹⁰ Investment in personnel involves retraining of existing I&A staff about the NFCSP goals, the philosophy of treating caregivers as consumers, caregiver diversity, operations, and reporting requirements.

Agencies might want to consider requiring certification of I&A staff, developing protocols (e.g., decision trees), and hiring specialized I&A staff experienced with caregiver issues. This suggestion applies both to staff who work on the telephone lines and those who take responsibility for online information or service requests. **Exhibit VII.11** describes the Caregiver Resource Specialist position created by the AAAs in North Carolina. The network might consider the addition of a caregiver consultant to the I&A staff who can address behavior management, scheduling, medication management, and other specific caregiver issues. In Atlanta, for example, the AAA hired a registered nurse (RN) to fill this role due to the health issues surrounding caregiving. The state of Indiana implemented standardized training through a contract with the Indiana Association of AAAs. Training components include basic orientation to the in-home services system and Medicaid waivers, customer service skills like dealing with difficult people, techniques for asking questions, use of the Internet and the I&A software, and time management.¹¹

Exhibit VII.11 **I&A Staff for Caregivers**

Title: Family Caregiver Resource Specialist Position

Affiliation: AAAs in North Carolina

Status: Operational

Target Population: Caregivers

Approach: Each AAA created a fulltime position for a Family Caregiver Resource Specialist. This individual is responsible for: 1) developing, implementing, and tracking the AAA's work plan for family caregiving support (subsumed in the Area Plan) in consultation with state-identified contacts; 2) leading program and resource development efforts (e.g., networking, grant writing, volunteer recruitment and training); 3) providing or arranging for direct services (e.g., public information activities, outreach, I&A, counseling, caregiver training); 4) establishing an adequate system for recordkeeping of individuals served, expenditures, and unmet needs; 5) developing an area publicity campaign for the NFCSP; 6) advocating for the interests of family caregivers; and 7) participating with AAA peers, the Division Specialist, and other staff members in support of program implementation and evaluation. The AAAs were encouraged to hire individuals for the Specialist position who had personal or professional experience in caregiving, or both. The SUA hired a Family Caregiver Program Specialist to work closely with the AAAs and oversee and support statewide development of the FCSP.

Contact Information: Chis Urso, Family Caregiver Program Specialist, Division of Aging, at chris.urso@ncmail.net or (919) 733-3983.

¹⁰ Lambert, T.N. (2001). *Information and Assistance*. Comments on Cheryl Schramm's issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

¹¹ Reinhard, S.C. and Scala, M.A. (2001). *Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States*. Prepared for the Public Policy Institute, AARP.

Structure the I&A Data Collection Process So It Captures Relevant Caregiver Information That Will Enhance Intake, Assistance, Follow-up, and Program Assessment Activities. Well-designed I&A systems with mechanisms for capturing key information can be used to inform service planning, outreach activities, capacity assessment, caregiver needs, training needs, advocacy, and other program operations related to supporting caregivers. The network will want to:

- Examine current software and assess its ability to integrate existing databases (including caregiver-specific data);
- Evaluate data collection needs beyond looking at “ease of burden” and toward how data collection can produce important evaluative information at the caregiver, local program, and overall program levels;
- Consider screening caregivers through the use of a structured interview; and
- Decide what information must be captured (basic information and beyond basic information) and when (what information is valuable to capture at initial intake and what information can and should be captured in future).

Washington’s FCSP uses one caregiver screening form for both “contact” and “screening” purposes. A contact is any call about or request for the FCSP, FCSP services, or family caregiving. Basic information is collected on all callers in two sections of the form. Additional information is collected from those callers who need something beyond basic information.

The program intake form used in the Alzheimer’s Demonstration is part of a one-time intake to gather basic demographic and functional abilities information on the person with Alzheimer’s Disease and on his or her caregiver, if one exists. Visit AoA’s Web site at <http://www.aoa.gov/alz> for information about the program intake form used by several states participating in the Alzheimer’s Disease Demonstration.

COUNSELING, SUPPORT GROUPS, AND TRAINING

Service Description

Counseling, support groups, and training refer to a range of individual and group services that assist caregivers in making decisions, solving problems, and gaining knowledge related to their caregiving role. ***Exhibit VII.12*** presents a sample of activities for the network to consider.

Exhibit VII.12 Caregiver Counseling, Support Group, and Training

<ul style="list-style-type: none"> ▪ Family conflict resolution ▪ Cognitive behavioral therapy ▪ Behavioral management skills training ▪ Problem-solving skills training ▪ Personal care skills training ▪ Counseling to caregivers of hospice recipients (pre-mortem and postmortem) ▪ Peer counseling ▪ Caregiver mentors ▪ Family counseling for grandparents ▪ Support group counselors ▪ Grief counseling ▪ Support group for former caregivers ▪ Education through caregiver camps 	<ul style="list-style-type: none"> ▪ Single session community workshops and education forums ▪ Lecture series followed by a discussion ▪ Short-term support groups (structured to educate about resources and caregiving skills) ▪ Long-term support groups (mutual information sharing, self-help among members) ▪ Psycho-educational and skills -building groups ▪ LTC planning ▪ Telephone-mediated groups ▪ Computer-mediated groups ▪ Videoconference training and education ▪ Education via Internet radio
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Strategies and Program Examples

Focus on Program Goals, Targeting Variables, and Type of Intervention in Determining the Design and Implementation of These Services. Toseland and Smith recommended that the network follow these steps:¹²

1. Carefully consider the characteristics of caregivers the program intends to serve (i.e., need for support; education; problem-solving, coping skills and personal care skills training; unique needs; and personal characteristics [of both the caregiver and care recipient]).
2. Define the goals of the educational or training program (i.e., the program should focus on prevention or remediation).
3. Define the target population, based on the program goals (i.e., cast a broad net over all caregivers or target caregiver subgroups).

Exhibit VII.13 presents a caregiver training and education program modeled on defined goals.

¹² Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

Exhibit VII.13

Training and Education for Dementia Caregivers

Title: The Savvy Caregiver: An Education Program for Family Caregivers

Affiliation: Alzheimer's Disease Resource Agency of Alaska and the University of Minnesota (School of Medicine, Department of Family Practice and Community Health)

Status: Operational

Target Population: Primary caregivers of persons with dementia currently receiving services and caregivers yet to be involved with the service system

Approach: The Savvy Caregiver is a formal educational program that focuses on improving informal caregivers' practice of providing care. The program seeks to: 1) increase the knowledge, skills, and outlook needed for caregiving; 2) reduce the stress and adverse effects associated with caring for an individual with dementia; and 3) improve the quality of life of family caregivers and their family members. The program consists of six didactic two-hour sessions that employ a combination of teaching methods, such as lectures, group exercises, role-playing, readings, and homework assignments.

Cost/Funding: The Alaska Commission on Aging (SUA) provided a \$64,037 grant for this two-year project.

Contact Information: Dulce Nobre at dnorbe@alz.alaska.com or (907) 561-3313.

Avoid a “One Size Fits All” Approach to Service Design and Implementation That Fails to Account for Different Types of Interventions Caregivers Both Need and Prefer. As Montgomery and Kosloski noted, adult children experience different needs than spouses. The former more likely will raise issues concerning sibling rivalry, family conflict, work-related conflict, and the effects of caregiving on their relationship with their spouse and children. Educational programs for this population could cover the disease process, community-based services, and legal and financial information. Support groups could address extending the support network and knowledge of community services. The latter more likely will broach issues about changes in their marital relationship, behavioral management concerns, and problems with their own health. In this case, education programs that cover coping skills, behavior management, and in-home supports might be a better fit. Support groups could cover changing relationship with a spouse, seeking and using supports, options for respite care, and how-to self care.¹³

Clearly, a flexible program design will prove critical to meeting the needs of diverse caregivers who have different preferences and schedules. Some people might prefer and benefit more from individual interventions, while others might be better suited to group

¹³ Montgomery, R.J.V. and Kosloski, K.D. (1999). *Family Caregiving: Change, Continuity and Diversity*. In P. Lawton and R. Rubenstein (Eds.) *Alzheimer's Disease and Related Dementias: Strategies in Care and Research*. New York, NY: Springer Publishing Company.

training. Toseland and Smith report that the empirical evidence on effectiveness shows the following:¹⁴

- Both individual and group interventions can be effective in reducing caregiver stress and should be considered.
- Caregivers with emotional problems might be better suited for individual training.
- Dementia caregivers benefit from interventions that are comprehensive, intensive, and individually tailored to caregivers' needs.
- Caregivers needing specialized information might be better served in smaller group settings.
- Group training could be more effective for caregivers in relation to building social support and overcoming isolation.
- With group interventions, structured psycho-educational programs containing a combination of education, problem-solving and coping skills training, and support might be more effective than single component support group programs.

In terms of support groups, one singular format usually proves ineffective because many people will be left out. Some caregivers might desire a support group early in the day (e.g., older spouse caregivers), while some prefer evenings (e.g., adult children). Some caregivers might want to participate in online support groups. Others will want to attend support groups at businesses during the employee lunch hour. Most support groups are just for caregivers, although some combine caregivers and care recipients (e.g., individuals with early-stage dementia simultaneously with their caregivers).

Providers have reported that support groups do not follow the mantra, "If you build it, they will come." Instead, to some people, support groups represent a weakness and admission of failure, especially for spouses. They can also represent a stigma or issue of pride in some communities. The term, itself, can be derogatory for certain minority groups. Montgomery recommended that support groups be held in familiar settings such as churches, giving them "legitimacy."¹⁵ Senior Spectrum AAA in Maine is attempting to rejuvenate poorly attended support groups by collaborating with existing groups to determine what needs exist and creating additional groups based on that need. Staff are presenting at existing support groups and gaining a better sense of group style so they can better inform caregivers of the groups that might best match their needs. Effectiveness of support groups depends on the type, scheduling, and content of the support group as well as on the interpersonal dynamics. Therefore, the leader of a support group should be appropriately trained to deal with small group interactions.

Many caregivers are unable to receive support outside the home or prefer not to do so. For this population, the network will want to consider in-home counseling, education,

¹⁴ Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

¹⁵ Montgomery, R.J.V. AoACarenet Listserv, January 30, 2001.

and support options. In addition, technology-based interventions might be convenient for rural communities, special populations dispersed over a large area, and caregivers who are unable to or wish not to leave the care recipient alone to attend an out-of-home group. Colantonio and colleagues reported that telephone support has proven effective as part of combination interventions and has been used as an alternative to support groups to increase satisfaction with social supports and disseminate information about dementia. They recommended that the support staff (professional or caregiver) receive adequate training in screening for depression and knowledge of appropriate follow-up. Also, the network should remain flexible when determining timing of telephone support to meet caregivers' schedules. Online support options include CD-ROM information series, email, distance education courses, caregiver chat, etc. Research suggests that caregivers using computer support tend to be younger and seek additional means of support (e.g., telephone, newsletter).¹⁶

Act Creatively to Leverage Resources. First, the network should evaluate what *partnerships* can enhance their support of caregivers' counseling, support groups, and training needs. Toseland and Smith recommend affiliating with local chapters of organizations (e.g., Alzheimer's Association, the American Cancer Society, and AARP) to develop educational and training programs for caregivers of specific disorders,¹⁷ like the example of in-home support and education in ***Exhibit VII.14***. Agencies will want to consider partnerships with organizations that have expertise in caregiver education and training such as Cooperative Extensions and hospice/end-of-life organizations to provide caregiver educational programs. Also, a local college, public library, hospital, or other health and human service organizations might offer the resources for interactive videoconferencing. This format could be particularly useful for experts and caregivers to engage in dialogue from remote sites.

Second, the network will want to look at *building on existing services*. Many service providers who currently support care recipients are in the position to expand their focus to caregivers. ***Exhibit VII.15*** presents a multi-component program for caregivers offered by a local homemaker provider.

As a third means of leveraging resources, the network will want to explore *economies of scale*, through cost-effective options to educate or train a large number of caregivers concurrently. ***Exhibit VII.16*** offers an example of statewide and local caregiver training conferences held in Washington, funded by the state unit and corporate support.

¹⁶ Colantonio, A., Cohen, C., and Pon, M. (2001, June). Assessing Support Needs of Caregivers of Persons with Dementia: Who Wants What? *Community Mental Health Journal*. 37(3): 231–243.

¹⁷ Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

Exhibit VII.14

In-Home Support and Education

Title: Caregiver In-Home Education and Support Demonstration

Affiliation: Council on Aging of Southwestern Ohio and the Alzheimer's Association

Status: Developmental

Target Population: Homebound high-risk, high-stress caregivers of persons with dementia

Approach: Care managers from the AAA identify caregivers at high risk who exhibit significant levels of stress resulting from demanding caregiving situations and alert the local Alzheimer's Association chapter. Professionals from the Alzheimer's Association then consult with the caregiver in the home. The program assumes that caregiving responsibilities would likely prohibit these caregivers from attending support group. The program teaches behavioral management techniques to curb problem behaviors that instigate caregiver stress. Educational issues addressed include eating, wandering, arguing, and communicating. After a few visits from the Alzheimer's Association professional, the caregiver receives a help line number for future use. Caregivers in this pilot program reported decreased levels of stress, high levels of satisfaction with the program services, and increased use in behavioral interventions.

Cost/Funding: Total annual program costs are \$15,000. Although the pilot began before Title III-E funds became available, the AAA will pursue continued implementation with the new NFCSP funds. The AAA reimburses the Alzheimer's Association by the hour. The cost per client ranges from \$55 to \$400, and 64 clients have been served.

Contact Information: Ken Wilson, Council on Aging of Southwestern Ohio, at wilson@help4seniors.org or (513) 345-8612.

Exhibit VII.15

Leveraging Existing Service Providers

Title: In-Home Caregiver Support

Affiliation: Visiting Nurse and Homemaker Services; the Division of Senior Affairs (SUA), New Jersey Department of Health and Senior Services

Status: Operational

Target Population: Any unpaid primary caregiver (must live with care recipient or visit regularly to assist with managing life activities)

Approach: Visiting Nurse and Homemaker Services, under contract with the state of New Jersey SUA, provides an in-home caregiver education and support program to caregivers at all income levels. The program was established in response to unmet caregiver needs resulting from services not covered under Medicare. Program services include home visits by a nurse to help with education about personal care, nutrition, disease specific information, community resources, and stress management. The program also employs a licensed clinical social worker and an advanced practice psychiatric nurse to provide short-term counseling. Referrals for caregivers in need come from hospitals, social services, and caregivers themselves. The program allows five educational and supportive visits per caregiver, serving approximately 16 to 20 families yearly.

Cost/Funding: An \$8,000 grant supports this program. Funding for the program is the same for each county.

Contact Information: Bonnie Mangle, Director of Special Programs, Visiting Nurse and Homemaker Services, at bonnie_mangle@toadmail.com or (609) 267-7417.

Exhibit VII.16

Caregiver Conferences to Train Caregivers

Title: Challenges in Caregiving: Giving Care, Taking Care

Affiliation: Washington Aging and Adult Services Administration (AASA is the SUA in Washington)

Status: Operational

Approach: The Aging and Adult Services Administration (AASA) holds an annual “Challenges in Caregiving: Giving Care, Taking Care” conference that offers caregivers practical, up-to-date information on resources and services available to help them in their caregiving role. The one-day event renders a chance to train and recognize a large number of caregivers at once. Assistance in arranging for respite services is available, making it a good opportunity for caregivers to receive the information they need. Additionally, AASA provides funding and technical assistance to AAAs to hold local caregiver training conferences for teaching caregivers practical skills they can use daily, providing current information on supportive services and resources, offering emotional support, and raising community awareness of caregiver issues. Between 1997 and 2000, AASA contracted with seven AAAs to hold conferences in 14 areas. The large AASA conference usually attracts between 350 and 400 attendees, while local AAA conference attendance usually ranges from 50 to 100 people, with the larger AAAs reporting attendance of up to 300.

Cost/Funding: AASA’s “Challenges in Caregiving: Giving Care, Taking Care” conference typically costs about \$15,000, with some free speakers. AASA contributes to almost half of that cost. Corporate support, resource exhibitor fees, and low registration fees for caregivers cover the rest. The AAA conference budgets for Fiscal Year 2001 were under \$1,500.

Contact Information: Hilari Hauptman, Program Manager, Aging and Adult Services Administration, at haupthp@dshs.wa.gov or (360) 725-2556.

Emulating *train-the-trainer models* represent a fourth strategy to leverage resources. “Powerful Tools for Caregiving,” detailed in **Exhibit VII.17**, is a popular train-the-trainer course that members of the network across the country have used. The course, modeled on the highly successful Chronic Disease Self-Management Program developed by Dr. Kate Lorig and adapted for caregivers by Dr. Vicki Schmall, is used extensively in Oregon and is shown to reduce caregiver guilt and anger while increasing caregiver self-care behavior and confidence. SUAs and AAAs should consider several options to cover the cost. In North Carolina, for example, AAAs interested in providing “Powerful Tools for Caregiving” were encouraged to consider co-sponsorship with other AAAs and with organizations such as AARP that might subsidize persons to attend the training.

Exhibit VII.17

Train-the-Trainer Approach to Family Caregiver Education Program

Title: Take Care of You: Powerful Tools for Caregiving

Affiliation: Legacy Health System, Portland, Oregon

Status: Operational

Target Population: Trains pairs of Class Leaders and Co-Leaders (Class Leaders should be professionals in the fields of aging, social work, health or human services with professional and/or personal experience in family caregiving; Co-Leaders should be community volunteers currently or recently engaged in caring for an older adult relative). Teams will then train caregivers of an older adult with a chronic condition.

Approach: Master trainers are trained by Legacy and then conduct training for Class Leaders and Co-Leaders. In Washington, six teams sent by AAAs attended an intensive four-day training session and committed to leading two training sessions in the 12 months following their attendance. In North Carolina, teams received half-day intensive training over a two-day period. The Class Leaders and Co-Leaders then conduct a six-week class series for caregivers (sessions of two and one-half hours). Caregivers learn a variety of strategies to ease their burden, including how to reduce personal stress, communicate their needs to family members and professionals, effectively deal with challenging situations, and make difficult caregiving decisions. The recommended class size of caregivers is between 12 and 15. The course was originally designed for caregivers of patients with Parkinson's Disease, AD, or stroke, but is has been deemed useful, as well, for caregivers of people with other chronic health problems and disabilities. Legacy Caregiver Services recently received a three-year grant from the Robert Wood Johnson (RWJ) Foundation to expand the program throughout Oregon and to rural and diverse communities, including translating materials into Spanish.

Cost/Funding: In North Carolina, the cost of the two and one-half-day intensive course includes instructor fees, curricular materials, and supplies. Additional costs, depending on class location, might include travel and per diem for instructors and participants and costs associated with classroom rental or refreshments. Estimated cost for an area assumed to be located away from a central location is \$4,800 (amounts to \$320 to \$400 per attendee). This includes in-kind contributions on one Master Trainer's time (two percent match) and indirect costs (26 percent) to North Carolina State University. Not included in this price are the additional costs as described above. The North Carolina SUA funded the Legacy training of Master Trainers. In Washington, the SUA funded the initial training of trainers at the cost of \$500 per attendee.

Contact Information: (for information about Washington's experience with this program) Hilari Hauptman, Program Manager, Aging and Adult Administration, at haupthp@dshs.wa.gov or (360) 725-2556 and Lynne Korte at kortelm@dshs.wa.gov or (360) 725-2545; (for North Carolina's experience with this program) Dr. Luci Bearon, Master Trainer, at luci_bearon@ncsu.edu or (919) 515-9146; (for more information from Legacy Caregiver Services) Alison Burrell at (503) 413-6578 or Sue L. Frymark at (503) 413-7430 and visit <http://www.legacyhealth.org/healthcare/caregiver/default.ssi>.

Lastly, *peer support and caregiver mentors* have proven successful in supporting caregivers and appear to increase the likelihood of their receiving further assistance. In Wisconsin, one of the AAAs developed a peer counselor system in which a psychiatric social worker from the mental health system trains and supervises caregivers to provide in-home caregiver support. Montgomery notes that one of the most successful aspects of

a support group often is the ability to connect two caregivers who then interact more informally, as “supportive friends.”¹⁸

Enlist Service Providers to Serve Caregivers at the “Reachable Moment.” A common issue that providers report is the difficulty with establishing and sustaining caregiver support groups. In addition to designing flexible services, providers must be able to recognize how appropriate the intervention is for an individual caregiver (identify the “caregiver marker”). And, once caregivers are involved in an intervention, the provider must understand that caregivers’ needs change. Service providers have a key responsibility to educate caregivers who are outgrowing their programs about other community resources so caregivers receive the right services at the right time. When a caregiver leaves a support group, for example, follow-up should ensure that he or she receives support in other ways. In effect, providers “become the conduit of moving the caregiver through the system.”¹⁹

Build In Training and Supervision for Individuals Implementing the Services, and Monitor Implementation. Toseland and Smith noted that consistent feedback to staff and trainers is essential to improving the design of education, training, and support workshops.²⁰ Even seasoned clinicians can benefit from close supervision, as ***Exhibit VII.18*** demonstrates. Audiotaping or videotaping of group sessions helps trainers improve their program implementation skills. And, as an ongoing activity, providers and administrators should compare program goals with what is actually delivered and the impact of these sessions. ***Exhibit V.4*** in ***Chapter V*** suggests the value of caregiver surveys, for example. Evaluations can include assessments of the effect of a particular program on members’ knowledge and skills, their ability to cope with or solve pressing problems, or their well-being. However, the goals of the program should guide the choice of outcome measures.

In addition, Toseland and Smith suggested that, at a minimum, caregivers should be asked about:²¹

- Instructor evaluation,
- Program usefulness,
- Features that were most and least helpful, and
- Issues that should be included in future programs.

¹⁸ Montgomery, R.J.V. AoACarenet Listserv, January 30, 2001.

¹⁹ Montgomery, R.J.V. AoACarenet Listserv, February 1, 2001.

²⁰ Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

²¹ Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

Exhibit VII.18

Responsive Trainers and Evaluative Issues of Caregiver Workshops

Title: Caregiver Workshops Demonstration

Affiliation: Central Ohio Area Agency on Aging (COAAA)

Status: Developmental

Target Population: Broad caregiver population

Approach: The AAA is designing and implementing, in each of its eight counties, four different workshops that address a range of caregivers' needs. The program consists of four two-hour sessions covering: 1) practical, financial, and emotional issues related to caregiving, including the caregiver's role and relationship to the care recipient; 2) moving, lifting, and transferring an older family member; 3) accessing a full range of services; and 4) preventing caregiver burnout. Participants can attend some or all of the workshops free of charge. The evaluative component to this program includes phone follow-up by another staff member to evaluate the workshop, regular meetings with all the trainers to make necessary adjustments to the workshops, and an ongoing literature review. Attendee response to the workshops has been positive, particularly at the rural sites. The program's success has been attributed to effective recruiting and marketing, flexible scheduling, highly skilled and responsive trainers, and well-developed written materials. An innovative feature of COAAA's marketing approach is free, four-hour workshops for aging services professionals, which are offered quarterly. To raise awareness and reach aging services professionals as a referral source, the professional workshop affords an overview of all the workshops. Additionally, the professionals are offered continuing education units (CEUs). The AAA plans to partner with counties to provide respite care so that more caregivers can attend.

Cost/Funding: The AAA received a two-year Demonstration grant funded by the Ohio Department of Aging and is currently funded through the NFCSP.

Contact Information: Lisa Durham, Community Education and Outreach Director, Central Ohio AAA, at durham@coaaa.org or (614) 645-7250.

RESPITE CARE

Service Description

Respite care is considered to be temporary, substitute supports or living arrangements to provide a brief period of relief or rest for caregivers. Under the NFCSP, respite is *caregiver focused*. It can take the form of in-home respite, adult day services respite, or institutional respite. "Respite should be regarded as an outcome, not a specific service."²² *Exhibit VII.19* offers examples of respite care.

²² Montgomery, R.J.V. Presentation at the AoA Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

Exhibit VII.19 Respite Care

- | | |
|---|---|
| <ul style="list-style-type: none"> ▪ Supervision ▪ Personal care ▪ Telephone reassurance (reminding care recipient to take medications; telephone companionship with the dementia care recipient while caregiver prepares dinner) ▪ Socialization (friendly visitor, intergenerational program) ▪ Accompanying a care recipient to appointments ▪ Elder sitting (allowing caregiver to attend training and support groups) ▪ Homemaking services | <ul style="list-style-type: none"> ▪ Expanding respite care beyond dementia caregivers ▪ Adult day services ▪ Respite camps ▪ Caregiver retreats ▪ Social, recreational, educational, leisure, or other activities for the caregiver ▪ Overnight placement of a care recipient in a licensed foster care or long-term care facility ▪ Overnight placement of a care recipient in a non-licensed care setting (neighbor, companion) ▪ Errand running |
|---|---|

Strategies and Program Examples

Coordinate Multiple Respite Programs to Expand Eligibility, Facilitate Access, and Avoid Duplication, While Making Program Differences Invisible to Caregivers. The number of state respite programs has grown considerably through state-funded, single-purpose programs and as a specific benefit under Medicaid Waiver programs. The type, eligibility criteria, and funding mechanisms vary considerably across states and at the local level, requiring the network to examine what respite options are currently available and for whom and what gaps exist. States might want to pursue intra-agency collaboration around respite standards and definitions. Although many respite services have been built around the needs of caregivers of relatives with dementia, the NFCSP offers an opportunity to extend respite support beyond the traditional focus of serving the Alzheimer's Disease population. ***Exhibit VII.20*** presents an AAA approach in Maine to supplement the state's dementia respite program.

Exhibit VII.20

Expanding Eligibility for Respite Care

Title: Family Caregiver Respite Program

Affiliation: Senior Spectrum, AAA (Maine)

Status: Developmental

Target Population: Caregivers of care recipients receiving no assistance from another state subsidized program

Approach: Based on community needs assessment and focus groups, the AAA will expand eligibility for respite beyond dementia caregivers receiving assistance from the State's Partners in Caring Respite Program. Caregivers eligible for funding are caring for an individual who: 1) receives no assistance from another state subsidized program; 2) completes a confidential interview with a caregiver consultant, including taking the Utah Caregiver Burden Scale; and 3) after completing the Caregiver Burden Scale within 48 hours of the initial interview, scores 39 or higher. The caregiver is assessed twice to ensure that the stress derives from more than just a situation (e.g., having a bad day). The Family Caregiver Respite Program will pay up to a \$500 annual limit for any provider the caregiver chooses among in-home, adult day service, or short-term overnight placement options. The caregiver receives a bill for services rendered and then sends the AAA (Senior Spectrum, in this case) a copy of that bill attached to a copy of an AAA request for reimbursement form. The caregiver then receives a reimbursement check.

Cost/Funding: The estimated annual funding amount is \$10,000.

Contact Information: Debra Halm, Senior Director, Senior Spectrum, at dhalm@seniorspectrum.com or (800) 639-1553 ext.119; Leslie Shaffer, Senior Spectrum, at lshaffer@seniorspectrum.com or (800) 639-1553 ext. 106.

To minimize confusion for caregivers and providers in accessing the full range of available support, coordination between caregiver respite programs and other home- and community-based programs that offer respite care should also be pursued.

Offer a Range of Respite Care to Meet Individual Caregivers' Needs and Preferences, Including In-Home and Out-of-Home and Single-Component and Multi-component Respite Programs. Family caregivers prefer and use in-home respite care more than any other respite type. In Washington's experience, nearly two-thirds of respite hours in the state respite program are expended in the home. Overall findings from the Alzheimer's Disease Demonstration Grants to States (ADDGS) program revealed that families using in-home respite instead of adult day services tended to be middle-income (i.e., ineligible for Medicaid), had higher activities of daily living (ADL) impairments, and had spouse caregivers. Still, other caregivers (e.g., those who work, desire time by themselves at home, require hospitalization, or plan a vacation) might prefer out-of-home respite care. ***Exhibit VII.21*** presents two examples of out-of-home respite. Programs that leverage family, friends, and volunteer systems (e.g., Faith in Action) to deliver respite care might be in a better position to offer a full range of respite options.

Exhibit VII.21

Out-of-Home Respite Care

Title: Georgia Mobile Day Care Program

Affiliation: Greater Georgia Chapter Alzheimer's Association, Augusta Area Chapter Alzheimer's Association, and Central River Savannah Area AAA.

Status: Operational

Target Population: Caregivers of older persons in rural or metropolitan areas (originally developed for caregivers of persons with Alzheimer's Disease)

Approach: With materials and supplies needed for the day, staff travel to a designated site (e.g., church, senior center). Depending on the needs of the community, each site is open five or six hours per day, one to three days each week. Staff return to a central location in the evening. They worked hard to build trust and credibility by using well-known community sites, partnering with local agencies, and hiring a local employee. Though staffing for each program differs, most programs employ up to two paid fulltime equivalents (FTEs). In addition, volunteers assist staff with program activities, such as providing stories and poems from the past.

Cost/Funding: The program costs are spread between two sites. Primary cost components comprise salaries, fringe benefits, travel, rent, and day center meals. In Fiscal Year 2001, the mobile adult day care program budget of Athens Community Council on Aging was \$68,616.

Contact Information: Cliff Burt, Alzheimer's Program Director, Georgia Division on Aging Services, at gcburt@dhr.state.ga.us or (404) 657-5336.

Title: Senior Respite Guest-House Program

Affiliation: Metropolitan Family Services-DuPage County (Illinois private, nonprofit provider)

Target Population: Families caring for individuals age 60 and older in need of 24-hour supervision

Approach: The agency operates two respite guest houses, each with a five-bed capacity, providing respite services from 1 to 30 days. The facility environment is home-like and does not offer nursing care. The houses arrange for personal care assistant service and provide 24-hour supervision, socialization, home-cooked meals served family style, activities, and outings staffed by volunteers. On referral, the family meets with the agency social worker who conducts an assessment, followed by a tour of the house so the care recipient can become acclimated to the surroundings. The program serves approximately 150 unduplicated families per year, with an average stay of six days. Repeat visits are encouraged and are opted by nearly three-quarters of the families. Caregiver counseling and consultation are integrated into the service components.

Cost/Funding: Annual program costs are \$350,000 to operate two guest houses with a fulltime social worker and two house managers. Although some families are subsidized, others pay according to a sliding scale. Sources of funding include the NFCSP, fundraising, United Way, and several grants. NFCSP funding for the program is provided through billing the AAA case coordination units.

Contact Information: Janet Driscoll, Director of Senior Services, Metropolitan Family Services, at driscollj@metrofamily.org or (630) 784-4840.

Varying circumstances of the caregiver and care recipient call for caregivers to be able to choose from a range of options. By the time caregivers seek or use respite care, they often have many other support and care needs. Respite care, by itself, is insufficient to produce positive caregiver outcomes. Therefore, the network will want to consider combining respite care with other forms of caregiver support. The Asian-Pacific Adult Day Services Program in Washington (an Alzheimer's Disease demonstration) offers adult day services, family education, family counseling, one-on-one counseling for caregivers, and linkage with other services such as transportation and home care. **Exhibit VII.22** presents an example of a local multi-component program.

Exhibit VII.22 Multi-component Program

Title: Caregiver Camp

Affiliation: Cabarrus County Department of Aging and Centralina Area Agency on Aging, North Carolina

Status: Developmental (Planned for June 2002)

Target Population: Adult caregivers caring for someone over the age of 60 or a grandparent caring for a grandchild 18 and under.

Approach: The county is holding a five-day (9am to 3pm) caregiver camp at the Cabarrus County Senior Center focusing on educational information and training for the caregivers. Fun activities to reduce stress will also be part of the program by introducing the caregivers to activities at the center. In addition, group or in-home respite will be provided to care recipients when their caregivers attend camp. Transportation will be provided, if needed.

Cost/Funding: The camp is offered at no cost to caregivers. Funding is provided by the NFCSP and other sponsors as contacted.

Contact Information: Chasity Stoker, Aging Services Coordinator, Cabarrus County Department of Aging, at clstoker@co.cabarrus.nc.us or (704) 920-3484; Cyndi Smart, Caregiver Resource Specialist, Cabarrus County Department of Aging, at cmsmart@co.cabarrus.nc.us or (704) 920-3484.

Seek Different Approaches to Improve Respite Care Use. Research indicates that services providing respite care to caregivers prove more effective when delivered in adequate amounts (frequency and duration) and at the appropriate time. Brief users of respite reflect those situations in which the service fails to meet their need. Brief use raises costs for both the family and the provider (i.e., turnover, increased need for marketing, increased staff time, filling spaces from which others could benefit).²³

Furthermore, respite care more likely succeeds when it avoids increasing perceived burden by the caregiver. Caregivers experience no relief, for example, when a care recipient refuses help or creates difficulties for caregivers for arranging help.²⁴ If the cost

²³ Montgomery, R.J.V. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

²⁴ Zarit, S.H. *Respite Services for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

of respite services exceeds the benefit, (e.g., transportation or personal care needs for the care recipient overwhelm a caregiver trying to prepare his or her loved one for adult day services), respite care is perceived as unhelpful.²⁵

Caregivers exhibit different patterns of use by respite type. The characteristics associated with in-home respite are: spouse caregiver, married, co-residence, high disability-level of care recipient, and White. Characteristics of those who tend to use adult day services are: adult child, single elder, younger, lower disability-level of care recipient, Hispanic, African American, and urban. Spouse caregivers tend to use less respite overall than all other caregivers.²⁶

The following strategies aim to gain caregivers' acceptance and appropriate use of respite services:

- **Identify structural and process barriers to respite care use.** The network should re-examine existing policies around respite provision, particularly rules that might encourage caregivers to delay respite care with the concern that they could need it more in the future. Likewise, more generous and flexible financial incentives might influence service use more than using more conventional care management means to link caregivers.²⁷

It is clear that the appropriate type and level of respite care differs among caregivers. Arbitrary caps on respite care could impede effective resource allocation among consumers with different levels of need, resulting in ineffective or inefficient service use.²⁸ By developing mechanisms for the caregiver consumer to gain more control over the process, the network realizes a greater chance of meeting the caregiver's respite needs.

- **Provide respite care through properly trained, reliable, and accommodating support staff.** Consumer satisfaction levels with respite care are more affected by things that providers do than by client characteristics. With in-home respite care, provider reliability is likely to reduce care-related strain, improve caregiver well-being, and ultimately result in more effective use.²⁹ Providers can be educated to demonstrate sensitivity to the needs of caregivers and the tendency for caregivers to feel that they are imposing. Caregivers, in turn, can be educated about: 1) how to communicate important caregiving routines to respite care staff; 2) how to determine

²⁵ Montgomery, R.J.V. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

²⁶ Montgomery, R.J.V. and Kosloski, K.D. (2001). *Change, Continuity and Diversity Among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

²⁷ Zarit, S.H. (2001). *Respite Services for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

²⁸ Montgomery, R.J.V., Marquis, Schaefer, J., and Kosloski, K.D. Profiles of Respite Use. (Forthcoming 2002). *Home Health Care Services Quarterly*. 20(3/4).

²⁹ Zarit, S.H. (2001). *Respite Services for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

the best times of day for respite and communicate that knowledge to respite staff; and 3) how to communicate with the care recipient before and after the respite care experience.³⁰ Caregivers more often perceive providers they know as the most reliable.

Choice of provider is one element of control that programs can offer caregivers. A trend has emerged for state respite care programs to become laboratories for consumer-directed programs for the elderly and their caregivers. Findings from the Family Caregiver Alliance (FCA)–funded multi-state study of in-home respite delivery models showed that the majority of consumers preferred a “direct pay” model to an “agency based” model.³¹ This conclusion suggests that states should seriously consider developing and instituting consumer-directed programs. **Chapter IX** offers further information about consumer-directed services for caregivers.

- **Change caregivers’ perception of respite to a beneficial support service by communicating the value of respite.** Awareness of a program and the availability of other secondary caregivers account for family decisions about seeking respite (e.g., a more extended network of caregivers actually keeps families from seeking help). Also, if a caregiver perceives a service as a poor match for his or her needs in terms of availability or disability level of the elder, the caregiver will reject the service.^{32,33}

The value, rather than the price, becomes the key issue for most caregivers considering respite care. Translating program features into benefits to the caregiver to communicate value is a potentially helpful practice. For example, in the case of adult day service, Henry advises letting the caregiver know that the center’s providing the care recipient a nutritious lunch relieves the caregiver of cooking and worry about the participant’s getting enough to eat. Moreover, she says that exercise programs seem to help participants sleep better at night. Henry suggests a marketing exercise for respite staff: list all program features and convert them into benefits to the caregiver. This practice helps the staff “sell” the program as well as indicates areas of the program that can be enhanced to benefit caregivers.³⁴ Some considerations for adult day service providers in enhancing support for caregivers include:³⁵

- Working caregiver convenience,
- Sandwich generation needs,

³⁰ Worchester, M. And Hedrick, S. (1997). Dilemmas in Using Respite for Family Caregivers for Frail Elders. (Vulnerable Populations Part I). *Family and Community Health*. 19(4): 31(18).

³¹ Feinberg, L.F. and Whitlatch, C.J. (1996). *Family Caregivers and Consumer Choice: Options for In-Home Respite Care* (Final Report). San Francisco, CA: Family Caregiver Alliance.

³² Kosloski, K., Montgomery, R., and Youngbauer, J. (2001). Utilization of Respite Services: A Comparison of Users, Seekers, and Non-Seekers. *Journal of Applied Gerontology*. 20: 111-132.

³³ Brooks, G. Executive Director, Western Illinois AAA, in Rock Island, Illinois AoACarenet Listserv, February, 2001.

³⁴ Henry, R.S. (1993). *Customers Need to See Value of Services*. Winston-Salem, N.C.: Bowman Gray School of Medicine of Wake Forest University.

³⁵ Nestler, J. Executive Director, Eastside Adult Day Services. Telephone interview. October 22, 2001.

- Spouse and adult children needs,
- Health problems of the caregiver,
- Providing support groups,
- Communicating benefits, and
- Physiological fear
(e.g., concerns about quality of life, feelings of guilt, concerns for safety).

A Caregiver's Reflection

"As we observed the staff's caring watchfulness and attentiveness to her, we knew her days were safe and that the place retained familiarity to her. The staff's watchfulness extended to me as Katherine's caregiver. They answered all my questions (many before I asked them) . . . and each day brought a gentle smile, a special moment recalled, a hearty laugh, or, sometimes, a fear. All in the intimate understanding of the woman we cared for together."

Katryna Gould

Communicating the value of respite for caregivers should also be directed to individuals and organizations that represent major referral sources: health care professionals (e.g., physician office personnel, discharge planners), community providers, and employers.

- **Respond to "information seekers" and "service seekers" with different strategies.** Newton and Henry developed a caregiver targeting framework that can assist network staff and respite providers in identifying how best to serve different types of caregivers.³⁶

Information seekers are individuals who might be caring for someone with early-stage Alzheimer's Disease or minimal impairment who is in denial about the diagnosis or the fact that he or she needs help. The adult day service could focus on offering caregiver education to this caregiver population rather than attempting to enroll the care recipients in the program. Providers could supply information about future service options and support in dealing with the psychological aspects of caregiving. Because information seekers are potential users, staying in touch is valuable. When the caregivers reach the servable moment, then, they will consider the benefit of adult day service.

Respite seekers need an occasional break from caregiving but have no desire for daily adult day service. This segment encompasses two subgroups: *givers* are individuals who want to provide maximum care but are physically and emotionally unable to do so, and *responsibles* are individuals who provide care out of a sense of duty but who might find little satisfaction in caregiving tasks. Respite seekers are moderate users for whom providers might consider offering support groups and education about additional services.

Care seekers desire all the assistance they can get and are ready for more fulltime and regular adult day service. This segment also contains two subgroups: *delegators* are individuals who want their caregiving problem fixed and might go for the first service available, and *balancers* are individuals who would like to provide the care themselves but, because of other responsibilities, are unable to do so. Particular about the kind of care, this group tends to remain closely involved. Care seekers are heavy

³⁶ Newton, G. and Henry, R.S. (1992). *Marketing Adult Day Programs: Targeting Caregivers to Reach Participants*. Winston-Salem, N.C.: Bowman Gray School of Medicine of Wake Forest University.

users for whom providers could offer extended hours, ancillary services, and counseling services.

Examine Program Goals, and Determine Caregiver Outcomes and Quality Standards for Respite Care Use. Currently, evaluation of respite care services and identification of measurable outcomes are at an early stage of development. Zarit noted the unlikelihood that any intervention will affect all aspects of the stress process (primary stressors, secondary stressors, and outcomes) for caregivers; rather, a respite intervention is likely to affect some areas directly and others, indirectly, or it might exert no effect at all.³⁷ **Chapter V** offers further information about outcomes for respite care. The network might contemplate partnering with a researcher to assist in developing caregiver outcomes and indicators for single respite services and multi-component programs to inform respite program outreach, design, and delivery.

National accreditation for adult day service has been available to providers since 1999 through the Commission on Accreditation for Rehabilitation Facilities (CARF).³⁸ Because many states have no regulations, certification, or licensure for adult day service, accreditation is a valuable option. Through CARF, accreditation becomes a:

- Management tool that sets direction for consumer satisfaction and program success according to each center's mission, purpose, and core values.
- Business strategy used in establishing goals and objectives with performance measures and measurable outcomes.
- Quality enhancement strategy used in defining priorities for action through strategic planning and for directing resources through budget considerations, monitoring, and forecasting.
- Marketing strategy that allows development of a market focus through identifying consumer needs and expectations.
- Quality assessment tool that can be recognized as a seal of approval for providers, regulators, caregivers, and care recipients.^{39 40}

SUPPLEMENTAL SERVICES

Service Description

Supplemental services are other services to support the needs of caregivers, as defined by the state. The category of supplemental services has a funding cap under the NFCSP (no more than 20 percent of the federal funding should be dedicated to this category). By

³⁷ Zarit, S.H. (2001). *Respite Services for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

³⁸ As of March 2001, 39 Adult Day Service programs, located in 18 states, were accredited.

³⁹ Nestler, J. (December, 2001). Accreditation for Adult Day Services: The Choice and What is CARF? Unpublished issue brief prepared for the U.S. Administration on Aging.

⁴⁰ See <http://www.carf.org/> for further information.

definition, supplemental services are meant to be flexible enhancements to caregiver support programs and are for the benefit of *caregivers*. **Exhibit VII.23** presents examples of supplemental services.

Exhibit VII.23 Supplemental Services

▪ “Caregiver survivor kits”	▪ Professional consultation (RN, OT, PT, MH, RD, JD)
▪ Purchase of caregiver training materials for lending libraries	▪ In-home nutrition and diet counseling
▪ Loan Closet with adaptive equipment	▪ Limited adult day service transportation
▪ Home modifications that benefit the caregiver	▪ Home safety interventions
▪ Registered nurse to conduct in-home assessments	▪ Assistive technology
▪ Homemaker services for money management	▪ Chore services and errand running by volunteers
▪ Emergency respite care	▪ Legal assistance
▪ Emergency alarm response system	▪ Telephone reassurance

Strategies and Program Examples

Limit Restrictions through More Flexible, Cost-Effective Methods. Because caregivers best know their own needs and each caregiver is different, the network should think about financing methods that allocate services to caregivers who need enhanced support. The process would take into account their needs for service type, timing, and amount. Some potential strategies include aggregate caps on supplemental services, individual caps on supplemental services, and integration of supplemental services with other services.

Consider Use of Professional Consultation for Assisting Caregivers with Financial and Legal Issues. Caregiver focus groups and surveys have commonly found that caregivers need guidance on financial and legal matters. The network could use supplemental services funding to go beyond what might be offered in a support group setting by contracting with professional consultants. Pierce County Aging and Long Term Care, Washington AAA, for example, is developing a service contract to provide professional consultation and legal assistance by an attorney. The elder law/legal assistance program will help caregivers with durable power-of-attorney matters and health care directives. An annual \$500 cap per caregiver exists for supplemental services.

Implement Simplified Categorization and Accounting of Supplemental Services to Allow for Greater Flexibility. One area of confusion rests with how to categorize and account for supplemental services, particularly if a voucher system is in place. As described by Cliff Burt of Georgia Division of Aging Services, Legacy Express is a self-

directed care model in which voucher books in the amount up to \$500 are issued.⁴¹ For Title III reporting purposes, each voucher is counted as a unit of service. In the database, some services are identified by whether the service was purchased with a voucher.

Remain Open to the Unusual. In thinking about what is an acceptable supplemental service, allow for the caregiver's circumstance to dictate the "solution." McGuire recommended that the network, instead of making a list all of the possible services a program will allow, should consider just those items or circumstances that would be unacceptable.⁴²

⁴¹ Burt, C. Presentation at the AoA Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 7, 2001.

⁴² McGuire, D. AoACarenet Listserv, April 30, 2001.